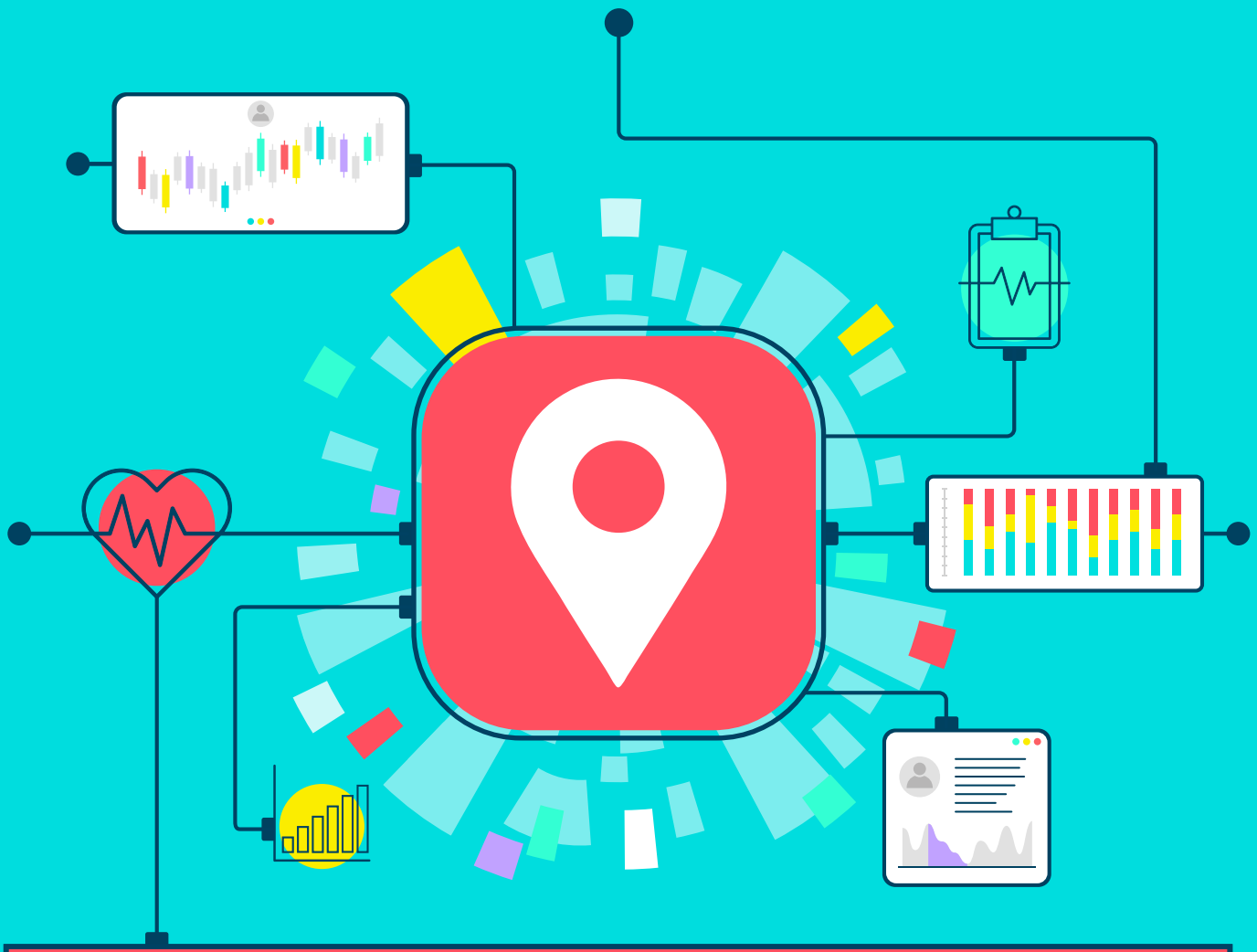
Understanding Patient Data



Understanding Patient Data in 2026:

Navigating public confidence in a changing health data system

A STATE OF THE NATION

Contents

Why a State of the Nation?

Health data sits at the centre of NHS reform. The Government's 10 Year Health Plan[1], the Data (Use and Access) Act 2025[2], the Life Sciences Sector Plan[3] and the 2026 Health Bill[4] (also known as the NHS Modernisation Bill), all place data at the heart of how health and care will be delivered.

Programmes such as the Single Patient Record[5], NHS Federated Data Platform[6] and Health Data Research Service[7] promise better connected care, research and innovation. But their success depends on more than technical delivery. Public confidence is now a critical part of the health data infrastructure.

A decade ago, the debate focused on whether people supported wider uses of health data. The evidence shows that most do – but that support is conditional and cannot be taken for granted. The challenge today is whether public confidence can be earned and sustained as the system becomes more connected, complex and contested, and as health data is increasingly understood through wider debates about the role of digital tools in everyday life, the power of global companies, geopolitical risk, and the terms on which public services depend on large-scale technology systems and suppliers.

UPD's first *State of the Nation*[8] identifies the factors that consistently determine public confidence and explores what they mean for the next phase of health data policy and implementation.

UPD's State of the Nation brings together multiple sources of evidence to understand public confidence in health data at a time of rapid system change.

Our evidence base includes:

- **A review of more than 100 UK evidence sources**, including nationally representative surveys, public dialogues, citizens' juries and qualitative research.
- **UPD's UK patient data sentiment tracker**, providing trend data on awareness, confidence, trust and support across three waves.
- **National media analysis**, examining how health data is portrayed and which narratives reach the widest audiences.
- **Social media analysis**, exploring how health data is discussed online and how narratives develop over time.
- **A review of patient and public involvement and engagement (PPIE)** across health data, mapping where and how the public is involved in decision-making (a live UPD project to be published in autumn 2026).

This evidence-base enables us to consider both population-level trends and the experiences, expectations and values that shape public confidence.

Together these insights provide one of the most comprehensive pictures currently available of public confidence in health data in the UK.

See the Appendix for further details of the supporting evidence.

1. https://www.gov.uk/government/publications/10-year-health-plan-for-england-fit-for-the-future
2. https://www.legislation.gov.uk/ukpga/2025/18/contents
3. https://www.gov.uk/government/publications/life-sciences-sector-plan
4. https://www.gov.uk/government/publications/health-bill-single-patient-record-fact-sheet/health-bill-single-patient-record-fact-sheet
5. https://spr.england.nhs.uk/
6. https://www.england.nhs.uk/digitaltechnology/nhs-federated-data-platform/
7. https://www.hdrs.com/
8. Although this report takes a UK-wide perspective, much of the available evidence and public debate is England-focused. We have included UK-wide and devolved nation evidence wherever possible, but the report does not examine in detail the distinct policy and governance contexts across Scotland, Wales and Northern Ireland.

What the evidence tells us

The system is changing faster than public understanding

Most people have only limited awareness of how health data are used. They are often uncertain about who can access data, for what purposes and what choices they have.

This creates a widening gap between the pace of policy change and the public's ability to make sense of it. National and regional programmes often have different purposes, governance arrangements and language, yet they are experienced by most people as parts of the same health data system. Distinctions that seem clear to policymakers are often less so to the public.

As a consequence, public understanding and confidence are disproportionately shaped by controversy. Health data has become more visible in public debate, but that visibility is highly uneven. Stories about risks, failures and perceived misuse reach 110x larger audiences than stories about the benefits of health data, which are often confined to specialist healthcare, research or technology spaces.[9] Risk narratives are also more immediate, personal and emotionally engaging, while benefit narratives often depend on technical explanation, institutional trust or longer-term public value.

This is important because risk and benefit narratives do not meet on equal terms. They are often led by different people, carried through different channels and encountered by different audiences. A positive story about health data use does not necessarily reach the people whose views are being shaped by controversy, nor does it extinguish concerns about privacy, commercial access, accountability or control. The result is a persistent narrative imbalance, particularly where public understanding is already limited.

Communications plans therefore cannot assume that more positive stories will simply balance out concerns about data use. They need to address risk directly, in the spaces where concern is forming, while also making benefits visible, concrete and relevant to wider public audiences.

110x larger audiences are reached by stories about risks, failures and perceived misuse rather than about the benefits of health data, which are often confined to specialist healthcare, research or technology spaces.

61% of the UK public say they know "very little" or "nothing at all" about NHS data practices.

Source: Survey with 7,100 people based in the UK (Health Foundation, 2023)

9. Understanding Patient Data and Portland (2026) *Health Data in the Headlines*

Conversations about risks and risk-led reporting

- **Media outlets:** The Register (1.7m), Daily Mail (39m), Byline Times (157k), openDemocracy (188k), The FT, Sunday Telegraph etc.
- **Themes:** Palantir, cybersecurity, privatisation, consent/opt-out, sovereignty
- **Voices:** Foxglove, Amnesty International, medConfidential, Good Law Project, Medact
- **Narrative:** Data commercialisation, Donald Trump, surveillance, incompetence
- **Monthly visitors:** 410m
- **Combined outlet reach:** 470m+ monthly unique visitors (national) plus 2.3m (campaigning)

NARRATIVE GAP

Conversations about benefits

- **Media outlets:** HSJ (85k), Digital Health (23k), Health Tech World (17k), pharmaphorum (50k), BMJ (3.5m), Pulse Today etc.
- **Themes:** AI deployment, digital transformation, research benefits, waiting list outcomes
- **Voices:** Health ministers, NHS digital leads, Tony Blair Institute, clinical researchers
- **Narrative:** Transformative potential, efficiency, global leadership
- **Monthly visitors:** 4.3m
- **Combined outlet reach:** c.4.3m monthly unique visitors

People increasingly use AI search tools and platforms to ask questions, compare explanations and make sense of complex issues. UPD-commissioned analysis[10] found that leading AI Large Language models generally give accurate, balanced explanations of patient data use, with broad agreement on core facts and safeguards. This creates an opportunity to improve public understanding by making trusted information more visible, clearly structured and easier for AI systems to find and cite.

10. Understanding Patient Data and Portland (2026) *Health Data in the Headlines*

Support is high – confidence is conditional

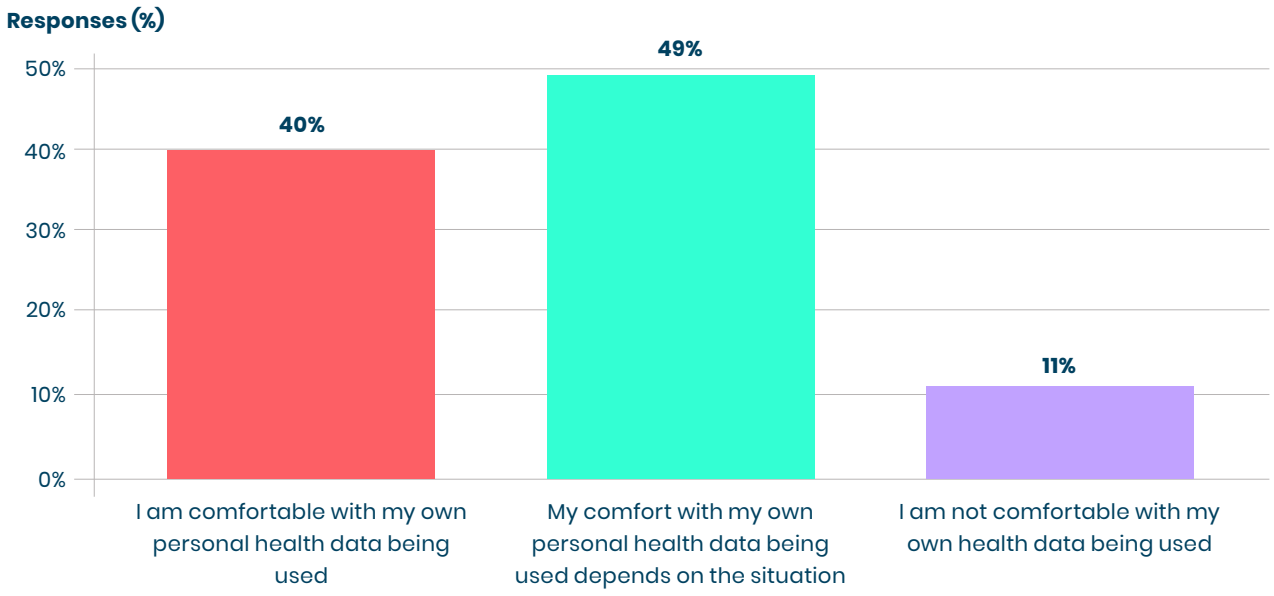
Despite the disproportionate reach of negative media coverage and low awareness of health data use, public support remains high. Across surveys, public dialogues, citizens' juries and deliberative research, there is consistent support for using patient data to improve care, support research and deliver wider public benefit.

There is particularly strong public backing for the use of health data for medical research, healthcare planning and improving public services, with support across survey studies often exceeding 85%.[11]

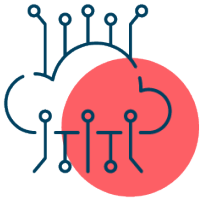
But strong support should not be mistaken for blanket approval. UPD's own nationally representative polling[12] shows that while most people (89%) report being comfortable with their personal health data being used, nearly half (49%) say that their comfort depends on the specific circumstances (see Figure 1).

Figure 1: Comfort with the use of personal health data

Nearly nine in ten people are comfortable with their health data being used, but almost half say this depends on the situation. Only 11% are not comfortable with their health data being used.



Source: Kantar/Understanding Patient Data (2026)



89% report being comfortable with their personal health data being used, but nearly half (49%) say that their comfort depends on the situation

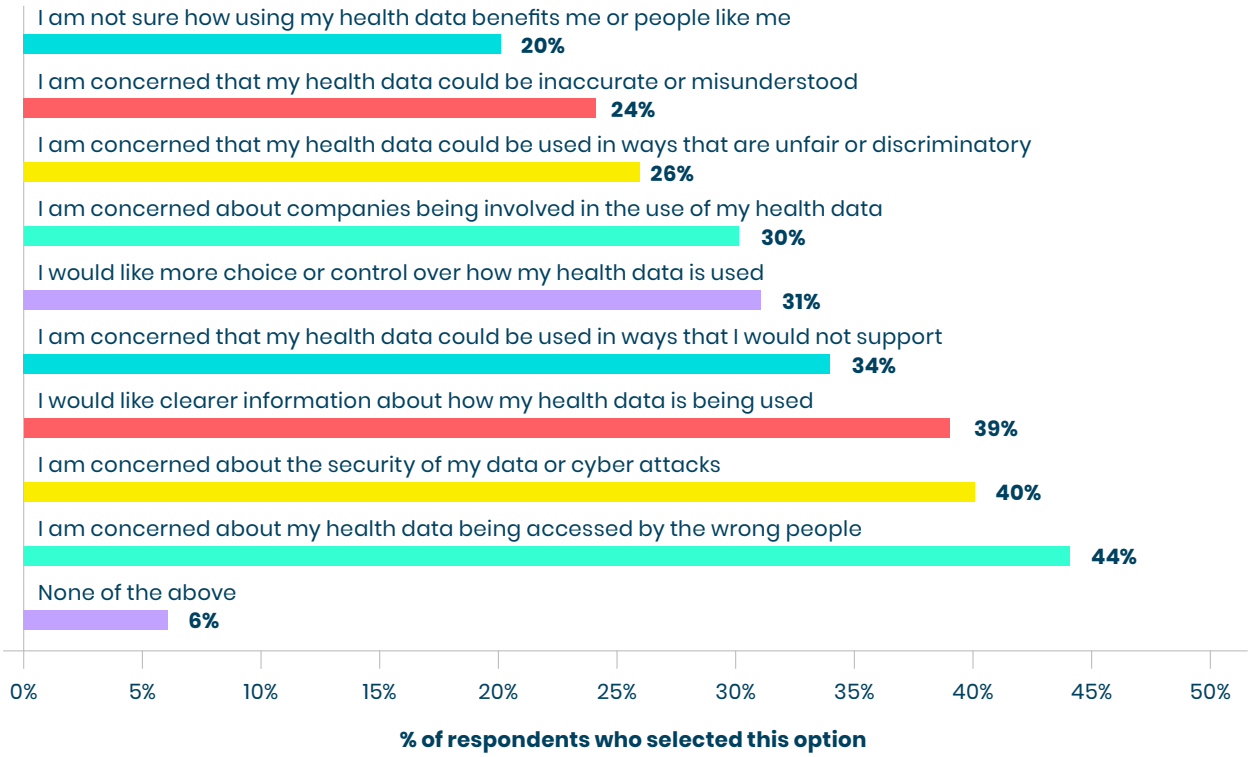
Source: Polling with 1,279 people based in the UK (Understanding Patient Data, 2026)

11. NatCen and ONS (2025) *Public Attitudes Towards Data Use in Statistics*; NHS England (2024) *Public Attitudes to Data in the NHS and Social Care*; Boston Consulting Group Centre for Growth (2023) *Towards a Healthier, Wealthier UK: Unlocking the Value of Healthcare Data*
12. Understanding Patient Data (2026) *UK Patient Data Sentiment Tracker: Wave 3 Findings*

Privacy, cybersecurity, unauthorised access and data breaches remain important public concerns (see Figure 2). The 2024 NHS England public attitudes survey[13] found that 83% of people trust the NHS to keep patient data secure. Our own nationally representative polling in May 2026 found that 52% of respondents were confident that the NHS (or equivalent health service in the devolved nations) has strong protections in place to keep health data safe[14]. This is a decline from 58% in July 2025.

Figure 2: Concerns and questions about the use of personal health data

The most frequently cited concerns are data being accessed by the wrong people (44%) and data security (40%), while 39% would like clearer information about how their health data are used.



Source: Kantar/Understanding Patient Data (2026)

44%

are concerned about their data being accessed by the wrong people.

Source: Polling with 1,279 people based in the UK (Understanding Patient Data, 2026)

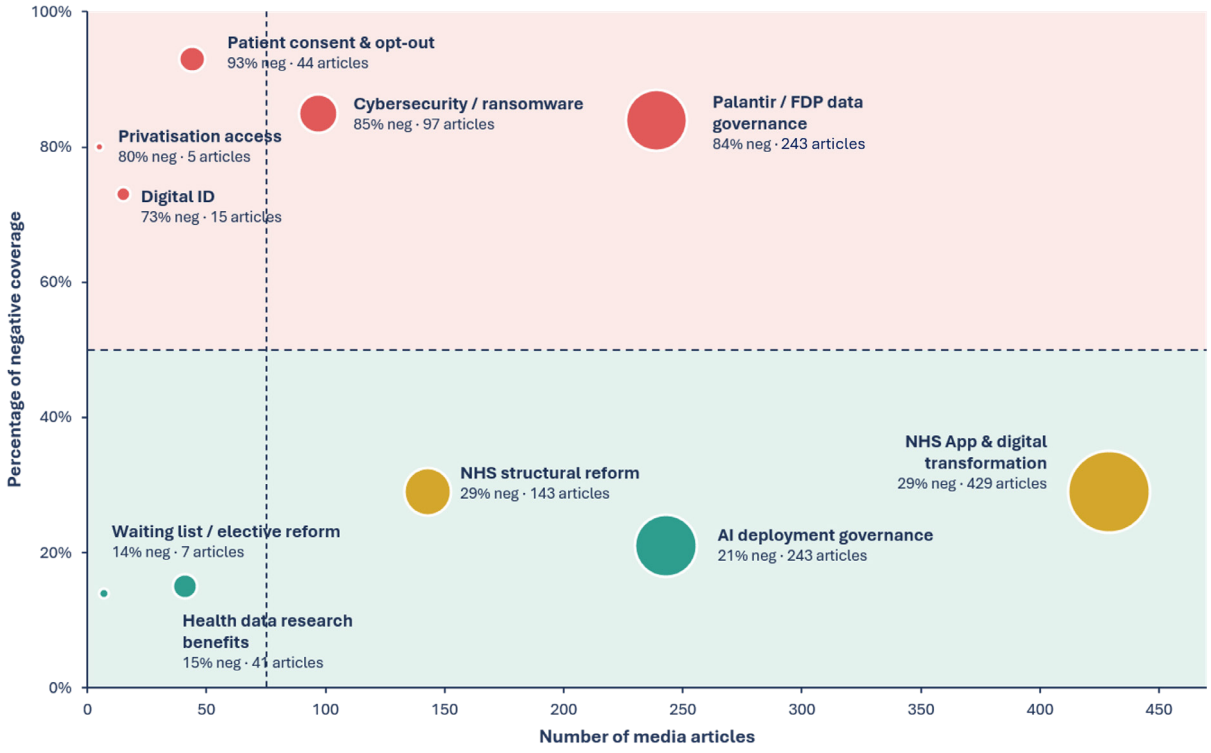
13. NHS England (2024) *Public Attitudes to Data in the NHS and Social Care*
14. The NHS England and UPD results are not directly comparable due to differences in question wording and response options. Notably, the NHS England survey only included agree/disagree options while UPD polling also included an additional "unsure" response option, which was selected by 27% of respondents. Negative responses were similar across the two, with around one fifth of respondents not trusting the NHS to keep their patient data secure (NHS England survey)/not feeling confident that strong protections are in place to keep their data secure (UPD polling).

Organisations must demonstrate that personal information is protected appropriately. But these safeguards are now part of a wider test of trustworthiness: media narratives are increasingly driven by governance and ethical concerns ranging from surveillance to the role of 'big tech' companies in public life. People also want to know how decisions are made, who scrutinises them and how organisations are held to account when things go wrong.

Understanding Patient Data commissioned Portland to analyse UK media coverage and public discourse on health data use over a 15-month period (March 2025-July 2026). The aim was to understand how competing narratives around the use of NHS patient data influence public attitudes toward data-sharing and institutional trust. The analysis encompassed 1,329 media articles sourced across national, healthcare trade, technology trade and campaigning outlets.

Figure 3: Key patient data themes compared by volume and sentiment

The five themes most likely to damage public trust – Palantir, cybersecurity, consent, Digital ID and privatisation – account for 30% of coverage and are 84% negative. Positive narratives about the benefits of using patient data are not reaching a wide group of people. Consent & opt-out is now the most one-sided theme (93% negative). Critically, these themes appear disproportionately in national press and campaigning outlets, with combined reach exceeding 474m monthly unique visitors. The themes that build trust – AI deployment, research benefits and waiting list reform – account for 22% of coverage and are 71% positive. But they sit largely in trade media (combined reach c.4.3m monthly visitors) and rarely reach a broad public audience.



Source: Understanding Patient Data and Portland (2026)

Conditions for public confidence

Evidence points to four conditions that consistently underpin public confidence:

1. **Clear public benefit**
2. **Trusted organisations and responsible stewardship**
3. **Visible governance and accountability**
4. **Meaningful public influence over decisions**

1 Clear public benefit

The strongest and most consistent finding across the evidence is that people are more willing to support the use of data when they can see a clear benefit for patients, the NHS or society, and less willing when benefits appear to flow primarily to private interests. This has remained one of the most stable findings in public attitudes research over the past decade.[15]

> In UPD's 2020 Foundations of Fairness[16] report with the Ada Lovelace Institute, participants were less concerned with who accessed data than with whether data-sharing was fair. They judged fairness by who benefited, who made decisions, and whether the public interest remained paramount. Key concerns included commercial partners extracting disproportionate value from NHS-held data, benefits being concentrated in particular organisations or regions, and important decisions being made without sufficient transparency or accountability.

This has important implications for national infrastructure such as the Health Data Research Service. As data access becomes easier and partnerships become more complex, public confidence is likely to depend less on the existence of commercial involvement than on whether clear governance demonstrates that benefits are shared fairly, decisions are transparent and public value remains the primary objective.

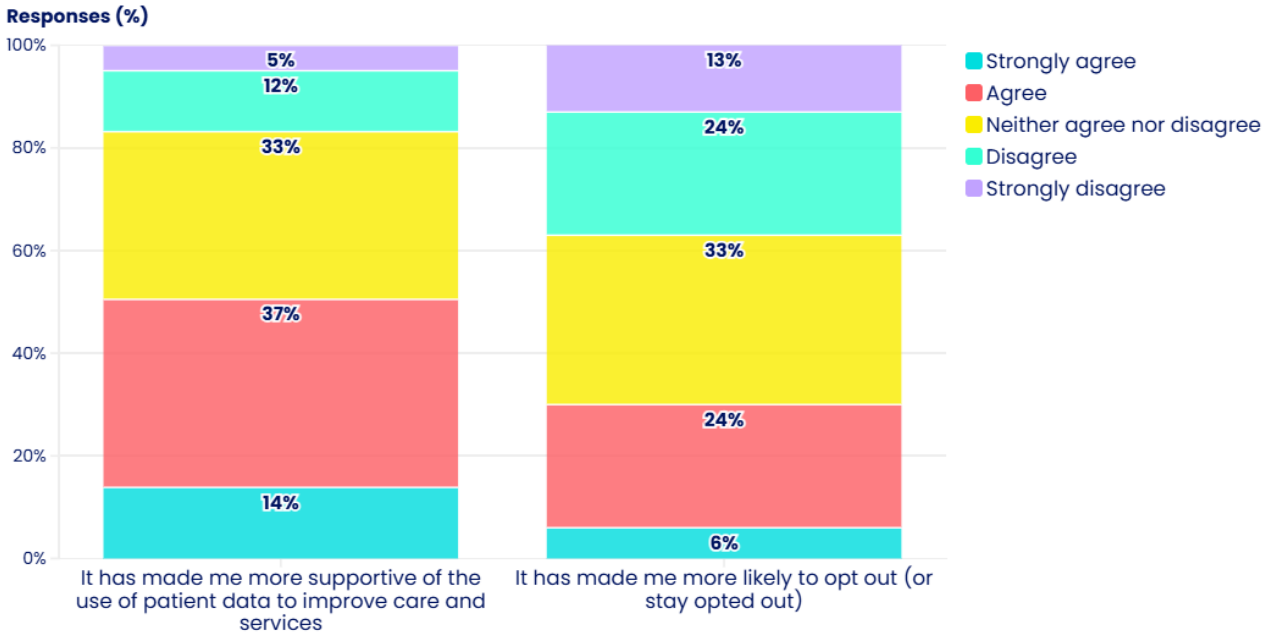
Public benefit also shapes how people judge commercial involvement, acceptable risk and the legitimacy of different uses of data. If public benefits are clear, meaningful and proportionate, research shows that participants are willing to support a wide range of uses, including some commercial partnerships.[17]

15. Stockdale et al. (2018) *"Giving something back"*; NHS England, Department of Health and Social Care, and Thinks Insight & Strategy (2025a) *National public engagement on the use of health and care data: Cohort 1 – principles of data use and access*
16. Understanding Patient Data and Ada Lovelace Institute (2020) *Foundations of Fairness*
17. Hopkins Van Mil and Understanding Patient Data (2021) *Putting Good into Practice*

For some programmes, such as the Single Patient Record, the benefit is more immediate and more visible. Our recent polling found strong public support for the programme, with many people reporting that media coverage had made them feel more positive about the use of health data (see Figure 4). By enabling more joined-up care, reducing duplication and giving patients easier access to their own information, it offers benefits that are both personal and collective.

Figure 4: Impact of media coverage about the Single Patient Record

Among the respondents who recalled seeing or hearing stories about a Single Patient Record (40%), 51% said media coverage made them more supportive of using patient data to improve care and services, compared with 17% who said it made them less supportive. Meanwhile, 30% said coverage has made them more likely to opt out (or stay opted out), compared with 37% who said it made them less likely to do so..



Source: Kantar/Understanding Patient Data (2026)
Graph only for respondents in England

The Single Patient Record also feeds into clear public appetite around expected benefits. Nine in ten people want better access to their health records,[18] 61% assume a Single Patient Record already exists,[19] and recent national deliberative research found strong support for making this a reality.[20]

But not every programme has such immediately visible benefits. Research and technology innovations often promise long-term improvements to health and lived experience, but their value is less tangible to the public. Where benefits are indirect or accrue over time, organisations must work harder to demonstrate why data are being used, how the public will benefit and why the proposed use is justified.

61% assume a Single Patient Record already exists[19]. Nine in ten people want better access to their health records.[18]

18. Sylvester et al. (2024) *Public back 'patient passports' to share medical records with any doctor*
19. Qa Research and Understanding Patient Data (2025) *Public Perspectives on GP Record Data*
20. NHS England, Department of Health and Social Care, and Thinks Insight & Strategy (2025b). *National public engagement on the use of health and care data: Cohort 2 – Linking Primary and Secondary Care Data.*

2 Trusted organisations and responsible stewardship

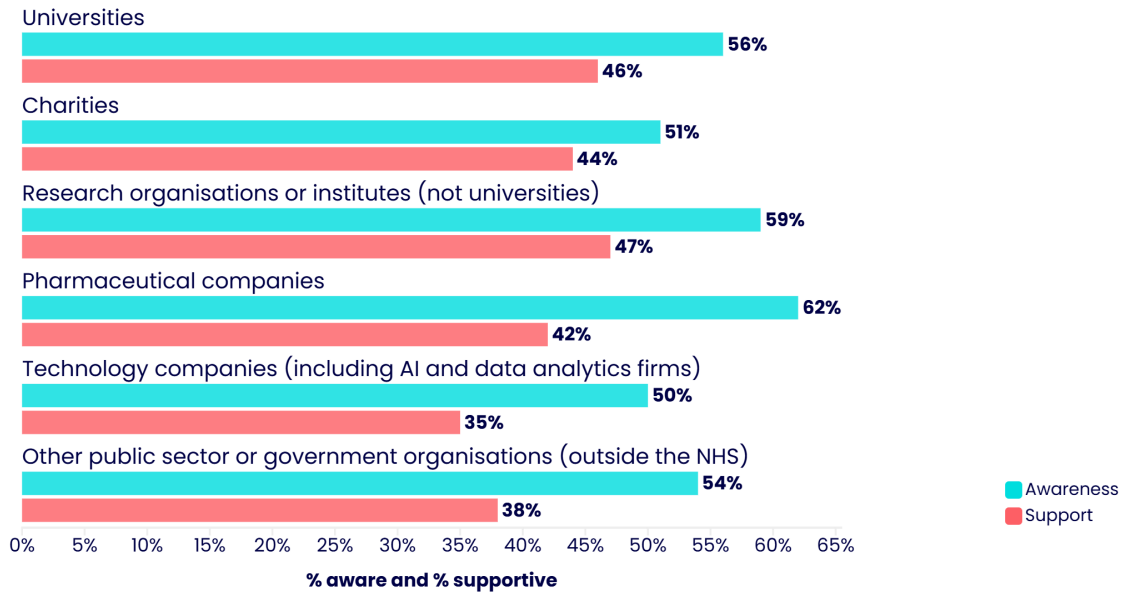
Across the evidence base, there is a remarkably consistent hierarchy of trust. The NHS, healthcare professionals and universities are among the most trusted organisations to use health data. Technology companies, social media platforms and insurers remain among the least trusted.

69% of people trust their GP practice with their data, vs. **34%** for national government

Source: Survey with 7,100 people based in the UK (Health Foundation, 2023

Figure 5: Awareness of, and support for, the NHS working with other organisations to understand and make better use of patient data

More people are aware of the NHS working with external organisations to understand and make better use of patient data than support these partnerships. Support is highest for partnerships with research organisations (47%), universities (46%) and charities (44%), and lowest for technology companies (35%).



Source: Kantar/Understanding Patient Data (2026)

Although attitudes towards commercial involvement are often more nuanced than headline polling suggests, organisations cannot assume that trust in the NHS automatically extends to delivery partners, suppliers or commercial collaborators.

While UPD polling shows that 62% of respondents have viewed their own health record, less than half of those have seen more than a limited summary.[21] If patients have never seen their own health record, how can they be expected to understand what is being shared, with whom, and for what purpose — or feel confident supporting its use?

21. Understanding Patient Data (2026) *UK Patient Data Sentiment Tracker: Wave 3 Findings*

The messenger matters too. Doctors remain among the most trusted professionals in Britain, while politicians are among the least trusted.[22] UPD's 2025 GP record research found people would prefer information about their health record to come from GPs.[23] This creates a tension for general practice which has shaped successive NHS data programmes and remains relevant today. Patients view GPs as trusted custodians of their most sensitive information, even as decisions about health data increasingly sit within national programmes and infrastructure. Questions about accountability therefore matter not only for governance but also for everyday conversations between clinicians and patients. If clinicians are uncertain about how information will be used or who is responsible once data leave the practice, they may find it harder to provide reassurance with confidence.

Sustaining public confidence will depend not only on robust technical implementation, but on ensuring that trusted clinical voices understand the programmes, can explain them clearly and remain confident in the safeguards that underpin them.[24]

3 Visible governance and accountability

The health data landscape is becoming more connected and, in many respects, more centralised. Alongside the Single Patient Record, initiatives such as the Health Data Research Service and the NHS Federated Data Platform are creating an a national data ecosystem (the Health Data Research Service is UK-wide).. At the same time, wider legislative and structural reforms will concentrate strategic responsibility for health data across fewer national institutions, with the Department of Health and Social Care playing a more prominent coordinating role. For the public, these developments are unlikely to be experienced as separate programmes. Instead, they may reinforce a broader perception that decisions about health data are increasingly made at national level, under political control, rather than by trusted local NHS organisations.

Building and maintaining trust will depend on clear and visible leadership alongside demonstrable evidence that national institutions are accountable, transparent and responsive over time.

Previous NHS data initiatives, from Care.data to GP Data for Planning and Research, demonstrate how quickly confidence can be undermined when wider debates about commercial involvement, accountability or government power become attached to a single programme.[25] The Single Patient Record programme is intended to support safer, more joined-up care. The Health Bill does not create a new legal route for using patient data for planning, research or other secondary purposes. It only allows the Single Patient Record to be used as a data source for these purposes where a separate legal basis already exists, such as the Health Service (Control of Patient Information) Regulations 2002. Existing safeguards still apply, including confidentiality duties and data protection law.

However, public confidence is shaped not only by what organisations are legally permitted to do today, but also by what people believe could happen in the future. As national infrastructure becomes capable of supporting additional functions over time, people naturally ask who will decide whether new uses are introduced, what safeguards will apply and how those decisions will be scrutinised.

As the Health Bill moves through Parliament and health data policy marches forward at pace, the challenge is to make governance visible so it is clear: who decides, who scrutinises, how the public interest will be protected and how decisions can be challenged.

22. Ipsos Veracity Index (2025)
23. Qa Research and Understanding Patient Data (2025) *Public Perspectives on GP Record Data*
24. At the time of publication of this report, the Department of Health and Social Care is running a programme of national engagement with GPs and practice managers to understand their views as decision-makers and trusted professionals, who often explain data choices to patients.
25. E.g., National Data Guardian (2016) *Review of Data Security, Consent and Opt-Outs; National Data Guardian (2026) National Data Guardian statement on NHS Federated Data Platform data access, in response to the Not With My NHS Data campaign*

4 Meaningful public influence over decisions

People are more supportive of health data use when they believe they can meaningfully influence the decisions that govern it. Across public dialogues, citizens' juries and deliberative research, people consistently express a desire not only to understand how health data are used, but to have opportunities to shape the decisions that affect them.

People want independent oversight combined with meaningful public involvement. They want to be able to influence and challenge system direction, without being expected to decide about every use of health data.

Since 2022, there has been substantial investment in public involvement and health data decision-making, including the Department of Health and Social Care and NHS England's national engagement programmes[26], dedicated patient and public involvement activity across the Secure Data Environment network[27], and the incorporation of public perspectives into governance mechanisms such as data access committees[28]. These developments mean the question is no longer whether public involvement exists. Instead, it is how consistently it is embedded, how clearly it is connected to decisions, and how well its impact is made visible.

The challenge is to act on existing and future insight about patient needs and expectations, include a diversity of communities in decision-making, and clearly demonstrate what changed as a result. As health data systems become more connected, confidence will depend on whether people believe they have had a genuine opportunity to shape them.

74% of people believe that the public should be involved in decisions about how NHS data are used.

Source: Survey of over 2,000 people (Understanding Patient Data and Ada Lovelace Institute, 2020)

Patient and Public Involvement and Engagement (PPIE) in health data use is widespread but unevenly embedded.

Evidence from our UK-wide review of the patient and public involvement and engagement landscape suggests that activity is most visible and most consistently supported in research and research-adjacent settings, where funding requirements, ethics processes, governance arrangements and data access procedures create formal opportunities for participation. These opportunities do not, however, always translate into meaningful influence. Activity is less visible and less consistently focused on data use itself in commissioning, service planning, quality improvement, evaluation and population health management, although there are examples of more developed practice.

Much of PPIE practice remains difficult to see and learn from, with limited evaluation of what PPIE changes.[29] The lack of transparency, coordination and sharing across organisations also drives expensive duplication, with programmes often commissioning new engagement activity, developing new materials or repeating similar conversations rather than building on existing insight and learning.

26. https://digital.nhs.uk/data-and-information/keeping-data-safe-and-benefitting-the-public/national-public-engagement-in-the-use-of-health-and-care-data
27. For example, *Yorkshire & Humber Secure Data Environment* (2024a, 2024b) and *Wessex Secure Data Environment* (2024, 20225)
28. https://ukhealthdata.org/trust-and-transparency/data-access-and-governance/
29. Lammons et al. (2025) *Measuring impacts of patient and public involvement and engagement* (PPIE), for a similar discussion about PPIE more broadly.

The opt-out paradox

The National data opt-out (England-only) provides one of the clearest behavioural expressions of how people exercise their agency within the health data system. Yet, the relationship between understanding, support and behaviours like opting out is not straightforward.

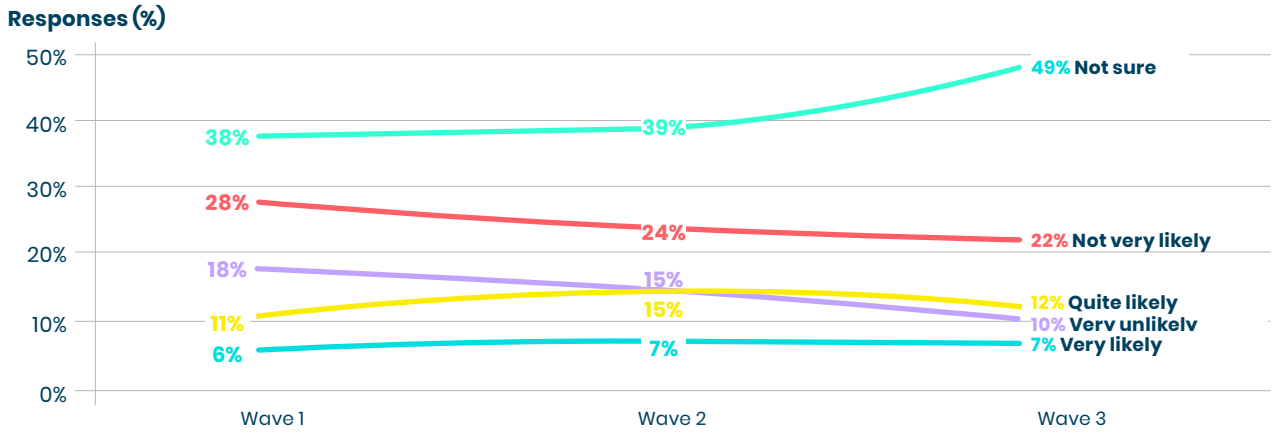
Opt-out rates vary. The National data opt-out dashboard shows, for instance, that more women have opted out than men (6.4% vs. 5.0%) and that opt-out is higher in London (7%) compared to the rest of England (23 June 2026 opt-out rate: 5.7%).[30]

As people learn more about health data, they often become more supportive of their use, but also more alert to risk and more likely to expect a say in how their data are used. Greater understanding can lead people to ask sharper questions and make more active choices. It builds informed engagement, not unquestioning acceptance. Our polling shows that people who opt out are more informed about how health data are used. They are more likely to be digitally engaged, more likely to have accessed their own health records and are often more familiar with national debates than the population as a whole.[31]

Opt-outs have important consequences, especially as they are not evenly distributed across the population, with some groups significantly more likely to opt out than others. This can introduce bias into datasets, reduce representativeness, limit the quality of research, affect service planning and ultimately diminish the public value that health data can generate. Previous controversies have also shown that sudden increases in opt-outs can lead to wasted investment, increased institutional risk aversion and missed opportunities to improve health and care.

Figure 6: Likelihood of opting out in the future

Among those who have not already opted out, uncertainty about future opt-out decisions has increased over time, rising from 38% in Wave 1 of UPD polling (July 2025) to 49% in Wave 3 (May 2026). Just 7% say they are very likely to opt out in the future, while 22% say they are not very likely and 10% say they are very unlikely to do so.



Source: Kantar/Understanding Patient Data (2026)

30. https://digital.nhs.uk/dashboards/national-data-opt-out-open-data
31. Understanding Patient Data (2026) *UK Patient Data Sentiment Tracker: Wave 3 Findings*

Exercising the right to opt-out should not simply be interpreted as opposition to health data use. It may reflect informed caution rather than rejection. For example, people may strongly support the use of health data for research, planning and improving care, while simultaneously questioning whether governance arrangements are sufficiently transparent and accountable. Treating opt-outs solely as evidence of declining public support risks overlooking the underlying concerns that drive behaviour.

Our research suggests that while controversies covered in the media appear to have little overall impact on people's support for health data use overall,[32] they can affect confidence and intention to opt-out. Controversy appears to lead to greater caution and closer scrutiny of governance rather than outright opposition to using health data to improve health and care.

National data opt-out levels appeared broadly stable through 2025, with more visible spikes emerging in May and June 2026 around specific high-profile media articles: Palantir 'unlimited access' revelations, cybersecurity incidents, Digital ID concerns. This differs from 2021, when National data opt-outs rose sharply in a concentrated period in response to the GP Data for Planning and Research programme[33], rather than appearing as smaller event-driven spikes. The public appears to discern between media volume and actual potential risk, responding to substance rather than noise. Opting out represents active engagement with the safeguards available to them, not rejection of data use per se. Opting out of one service or data share is not the same as an outright rejection of data sharing principles more broadly.

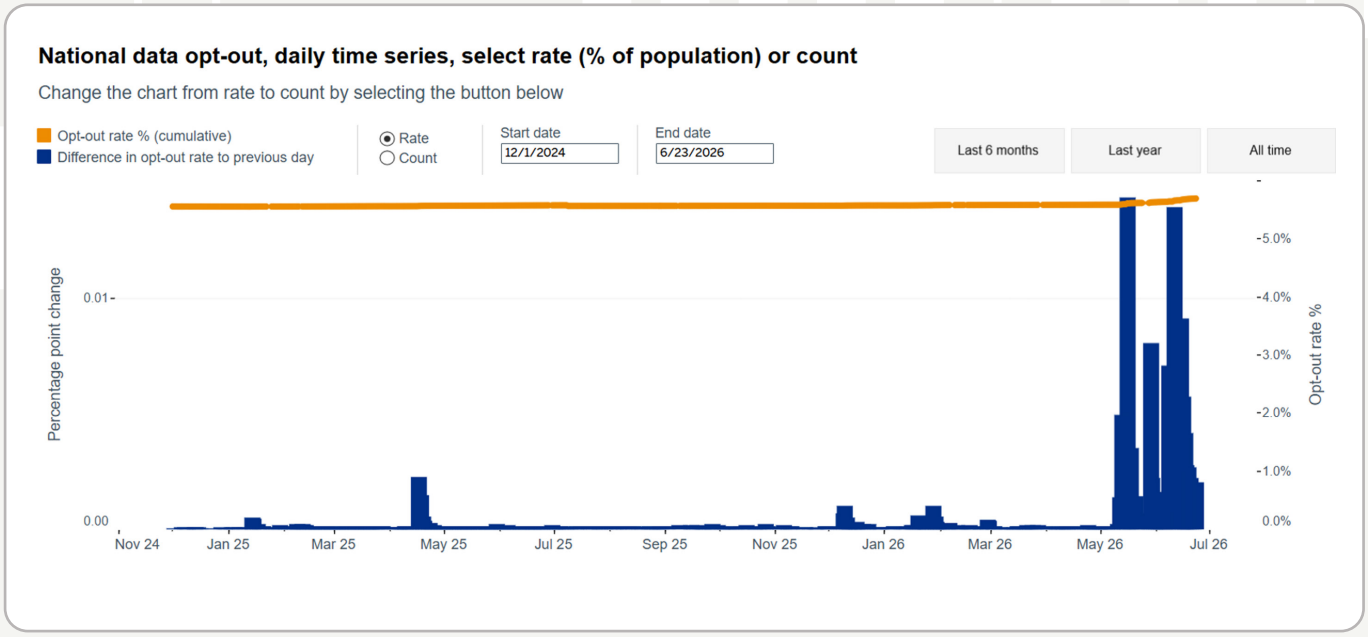
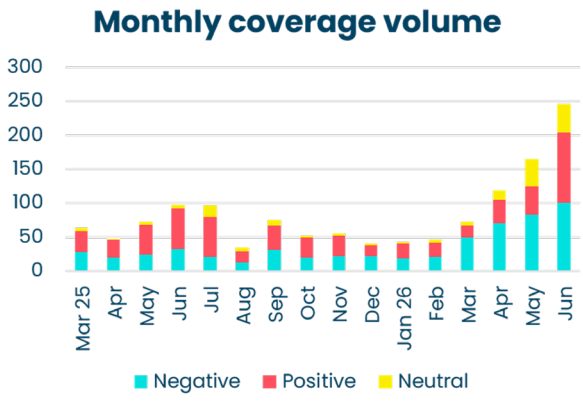


Figure 7: There were 143 stories related to Palantir /The NHS Federated Data Platform in May and June 2026 alone.

Despite an uptick in positive stories as well as negative ones, this activity seems to correlate with spikes in opt-out data in the Spring 2026.



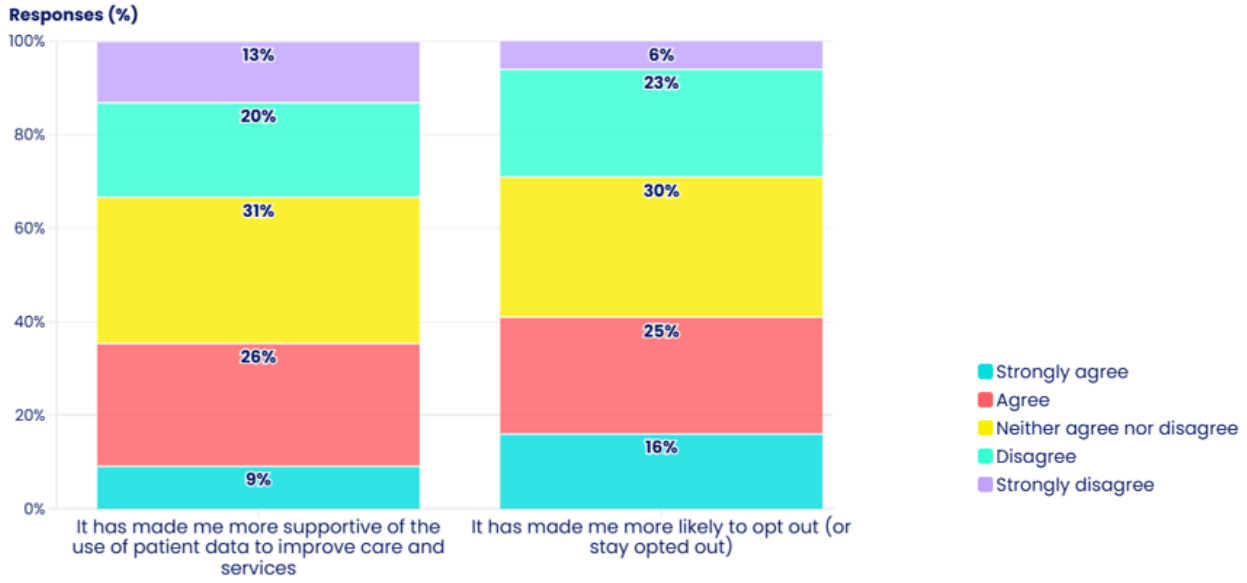
Source: Understanding Patient Data and Portland (2026)

32. Recent national stories about the NHS Federated Data Platform, Palantir and UK Biobank did not appear, on balance, to reduce public support for using health data. See Understanding Patient Data (2026) UK Patient Data Sentiment Tracker: Wave 3 Findings
33. In 2021, more than 1.3 million people opted out in a single month following coverage of the GP Data for Planning and Research programme, taking the opt-out rate from 2.77% to 4.97%. See Tazare et al. (2024) NHS National data opt-outs

Results from our polling suggests that Palantir coverage had little impact on people's support for data use but may have had an influence on opt-outs (see Figure 8). This is particularly pertinent given that NHS England currently describes the NHS Federated Data Platform, delivered by Palantir, as supporting direct care delivery and states that the National data opt-out does not therefore apply to its current use.

Figure 8: Impact of media coverage about the Palantir

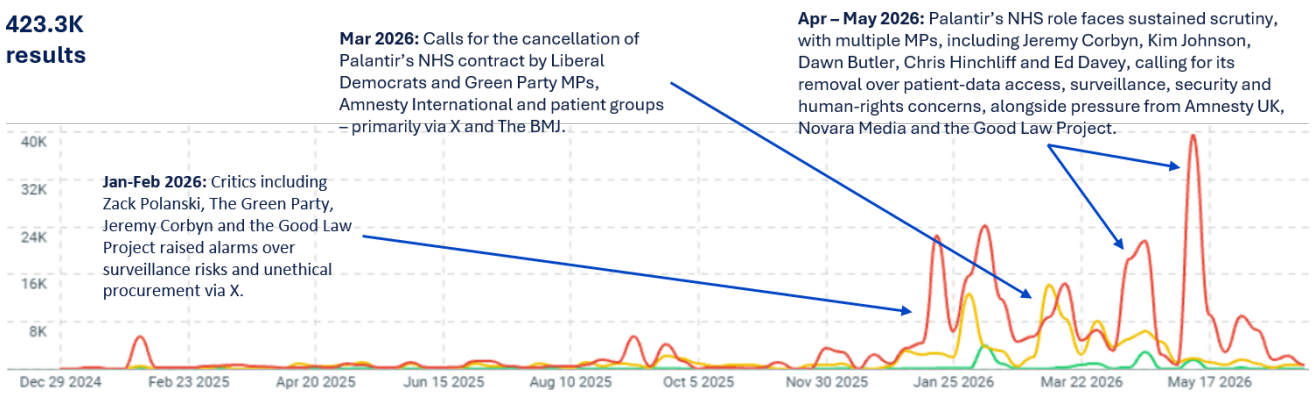
Among the respondents who recalled seeing or hearing stories about Palantir (33%), 35% said that seeing the news stories about Palantir made them more supportive of the use of patient data, compared with 33% who said it did not. Meanwhile, 41% of respondents said that seeing the news stories about Palantir made them more likely to opt out (or stay opted out), compared with 29% who said it did not.



Source: Kantar/Understanding Patient Data (2026)
Graph only for respondents in England

Figure 9: The Palantir contract debate links into many wider controversies

A detailed timeline highlights key events and actions related to Palantir's NHS contract, including calls for cancellation, parliamentary scrutiny, and concerns raised by various political and human rights groups. The majority of online conversation on this topic is happening on X and is highly negative with spikes driven by both media moments and individual tweets.



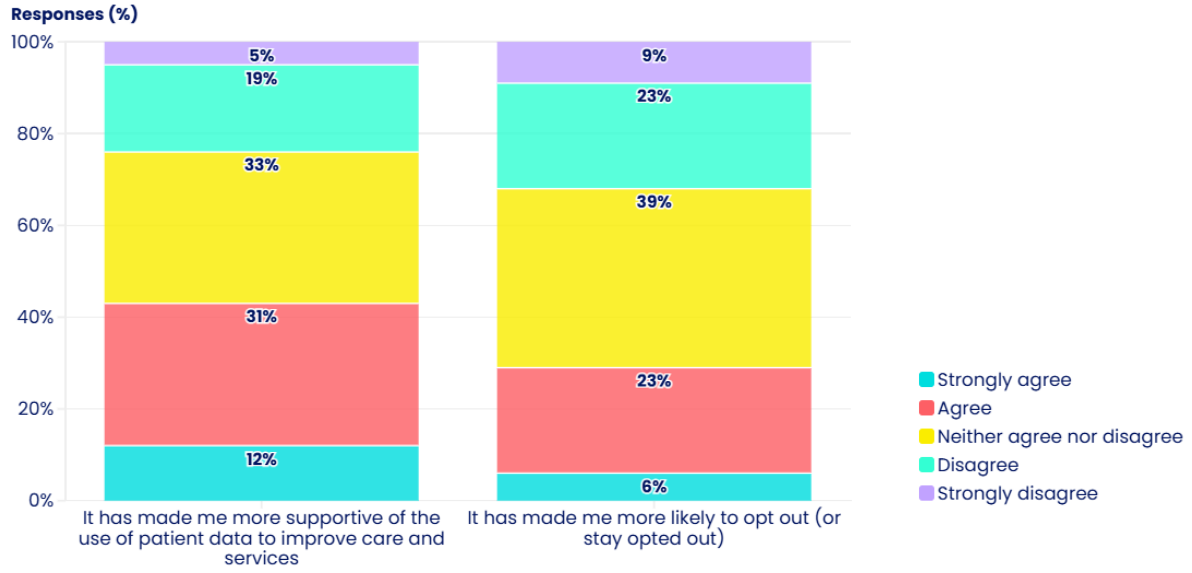
34. Understanding Patient Data (2026) *UK Patient Data Sentiment Tracker: Wave 3 Findings*
35. https://www.england.nhs.uk/digitaltechnology/nhs-federated-data-platform/security-privacy/nhs-fdp-privacy-notice/

But media coverage does not always have the reactive impact organisations fear. The recent UK Biobank coverage was serious: stories described participant data being offered for sale in China[36], alongside wider questions about access arrangements and governance. Given the nature of these allegations, the limited visible public reaction is striking. In UPD's recent public perceptions sentiment tracker, 43% said the stories made them more supportive of the use of patient data, compared with 24% who said they did not. UK Biobank has seen small numbers of participants withdraw following negative coverage, but these stories do not appear to have been associated with wider spikes in opt-outs. Nor is it fully clear why the reaction was so contained.

Our polling suggests that many people remained supportive of UK Biobank and the broader use of health data despite seeing the stories (see Figure 10). This should not be read as complacency or indifference. Rather, it suggests that controversy does not translate automatically into withdrawal of support, particularly where people still see public value and where organisations respond publicly, clarify governance, engage participants and make decision-making more visible. The lesson is not that controversy can always be avoided, but that legitimacy depends on organisations being able to explain, justify and, where necessary, adapt their approach.

Figure 10: Impact of media coverage about the UK Biobank.

Among the respondents who recalled seeing or hearing stories about UK Biobank (31%), 43% say media coverage has made them more supportive of using patient data to improve care and services, compared with 24% who say it has made them less supportive. Meanwhile, 29% say coverage has made them more likely to opt out (or stay opted out), compared with 32% who say it has made them less likely to do so.



Source: Kantar/Understanding Patient Data (2026)
Graph only for respondents in England

36. BBC News (2026) *UK Biobank health data listed for sale in China, government confirms*

Choice should be meaningful and usable

Patient choice is important – but it must be meaningful and usable. Current arrangements are still widely described as confusing and difficult to navigate. Many people are unsure what choices are available to them, or whether they have already exercised them.

1/4 of respondents said they had opted out of health data sharing across three waves of UPD polling[37]. This should not be read as a direct comparison with the National data opt-out[38] rate (5.7% on 23 June 2026), which applies in England, and is only one of several routes by which people may restrict how their health data are used. However, the gap between reported opt-out behaviour, and recorded National data opt-out rates suggests, at a minimum, significant public confusion about what people have opted out of, which choices apply, and what those choices mean.

This gap creates both a risk and an opportunity. If greater awareness, easier access through the NHS App, or the current review of the National data opt-out by the Department of Health and Social Care leads many more people to opt out without clear understanding of the consequences, it could affect the quality, representativeness and value of health data.

But the answer cannot be to make choice less visible. People need transparency, agency and simple routes to exercise their rights. The priority should be to ensure that choices are easy to find, (including how to opt out as well as opt back in), easy to understand and supported by clear information about what opting out does, *and does not*, mean.

Simplicity, visibility and clear communication are therefore as important as greater granularity. The current National data opt-out review is a timely opportunity to strengthen the relationship between transparency, agency and public confidence.

89% of people support a single NHS mechanism to choose how their data are used

Source: Survey with 29,275 people based in the UK (Jones et al., 2022)

The proposed Single Patient Record programme could strengthen the relationship between transparency and agency. Although important questions remain about how the arrangements will operate in practice, enabling people to view more of their health information through the NHS App, identify inaccuracies and request corrections could make data use more visible and give people a more active role in the stewardship of their own information.

37. Findings from the latest polling: Understanding Patient Data (2026) UK Patient Data Sentiment Tracker: Wave 3 Findings
38. https://digital.nhs.uk/dashboards/national-data-opt-out-open-data

Innovation does not get an automatic social licence

New technologies do not face a different set of public expectations. People apply many of the same tests as they do to established uses of health data: is there clear public benefit, are appropriate safeguards in place, and are decisions made transparently and accountably?

Most people are not inherently opposed to innovation.[39] They are cautious when the purpose, risks or governance arrangements are unclear.

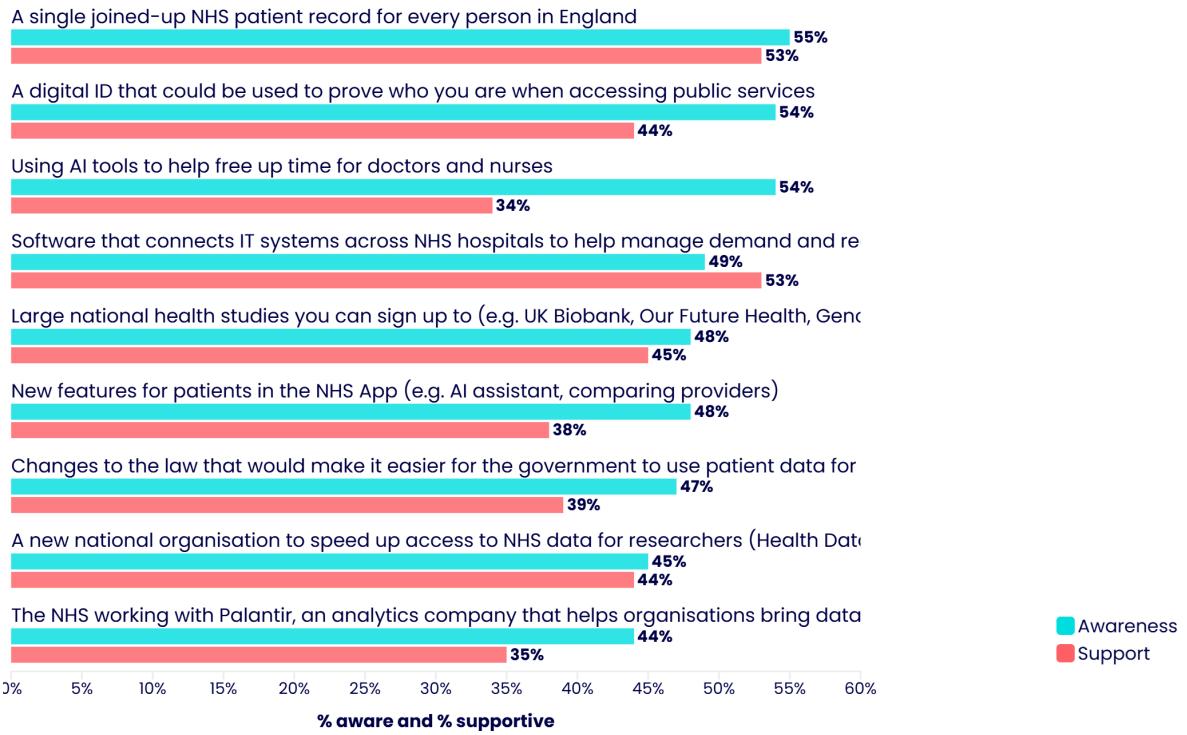
Confidence is lower for newer applications than familiar uses of patient data. Where people have limited understanding of how technologies work or who is responsible for them, uncertainty rises.

42% agree that the speed of developments in science and technology means that they cannot be properly controlled by the government

Source: Survey with 5,281 people based in the UK (Ipsos, British Science Association and UK Research and Innovation, 2025)

Figure 11: Awareness of, and support for, NHS working with other organisations to understand and make better use of patient data

Awareness and support vary considerably across different initiatives. The highest levels of both awareness (55%) and support (53%) are for a single joined-up NHS patient record, while support is lowest for NHS partnerships with Palantir (35%) and the use of AI tools to free up time for doctors and nurses (34%)



Source: Kantar/Understanding Patient Data (2026)

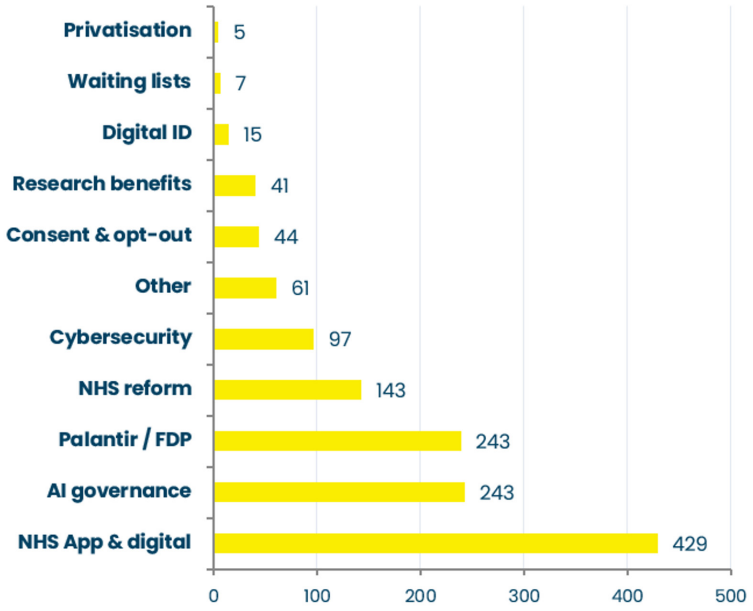
39. Healthwatch England (2026) study shows that public support for the NHS rollout of AI scribes (ambient voice technology) is split relatively evenly between support and opposition, and that lack of awareness and trust in how data are used is furthering discomfort and affecting what sensitive information patients disclose to their doctors.

In UPD's public polling, **'Using AI tools to free up time for doctors/nurses'** has the biggest gap between awareness and support – whilst **54%** of respondents were aware of this, only **35%** feel supportive of it.[40]

As health systems become more dependent on AI, cloud services and large-scale digital infrastructure, questions of trust are increasingly tied to wider debates about technological sovereignty, resilience and national control.

Figure 12: AI, Palantir and NHS reform dominate the media debate

Across 1,329 media articles related to health data from March 2025 to June 2026, AI has dominated coverage, split in topic between transformative promise and governance fears. NHS England reform creates a new political backdrop, while Palantir's NHS Federated Data Platform contract has become a proxy for sovereignty concerns with 84% of coverage negative, linking NHS data to US tech, U.S. Immigration and Customs Enforcement (ICE) connections and data leaving UK jurisdiction.



Source: Understanding Patient Data and Portland (2026)

The public debate around the NHS Federated Data Platform and Palantir shows how quickly technical programmes can become proxies for broader questions of public confidence. Media coverage and public discussion have often focused less on the platform's current function than on what the choice of supplier is perceived to represent. Coverage focuses on commercial influence, national sovereignty, the growing role of global technology companies in public services, and the extent to which governments retain control over critical digital infrastructure. Debates about individual suppliers therefore often become shorthand for deeper questions about power, accountability and control.

The implication is clear: support for innovation cannot be assumed simply because a technology is potentially transformative. Nor should innovation be treated as requiring a fundamentally different approach to public confidence.

Media debate sees patient data increasingly discussed through the lens of sovereignty, surveillance and governance, with high levels of opposition to NHS data contracts being awarded to US technology firms.[41]

40. Understanding Patient Data (2026) *UK Patient Data Sentiment Tracker: Wave 3 Findings*
41. *Eko survey with 2,097 adults in the UK* (delivered by YouGov in July 2026) found that 76% thought it was unacceptable for US technology firms to handle patient medical data on behalf of the NHS.

There is no single public view

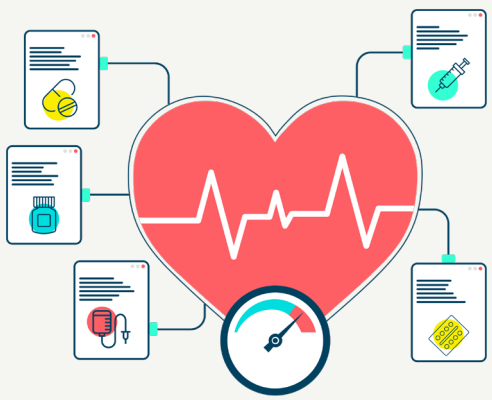
Public confidence about health data use cannot be understood as the views of a single, uniform public. NHS England's 2024 public attitudes research[42] identified six attitudinal segments, showing that people differ not only by demographic characteristics, but also by their knowledge, behaviours, levels of trust, perceived benefits and concerns about how data could be misused. There is also variation in attitudes across age, ethnicity, gender, health status, socioeconomic circumstances, geography and digital engagement.

The strongest pattern is not demographic but experiential, with people's views about health data often shaped by their experiences of healthcare itself. People who report positive experiences of healthcare are generally more willing to share data and more confident that it will be used appropriately.[43] Those whose experiences have been negative are more likely to question how information will be used and whether organisations can be trusted to use it fairly.[44]

Trust in health data is also often built, or damaged, through interactions with health data. People describe inaccurate records, missing information, difficulties correcting mistakes and insensitive clinical notes as experiences that undermine confidence in wider data-sharing initiatives.

Building confidence requires involving a wider range of communities in decisions, ensuring governance arrangements are demonstrably fair, and recognising that different groups experience both the benefits and the risks of data use differently.

For many communities, concerns about health data are inseparable from wider experiences of inequality. Data availability itself reflects unequal access to healthcare: communities that are less able to access services, receive poorer care, or have negative experiences recorded in clinical systems may also be less visible, less accurately represented, or misrepresented in the data used for planning, research and innovation. People therefore fear not only that health data could be used in ways that reinforce existing inequalities, but that the systems collecting, governing and using data may reproduce those inequalities from the outset. Concerns have been identified among transgender people, disabled people and other minoritised groups, where worries about stigma, discrimination and unequal treatment shape perceptions of data sharing and governance.[45]



42. NHS England (2024) *Public Attitudes to Data in the NHS and Social Care*
43. Kirkham et al. (2022) *Experience of Clinical Services Shapes Attitudes to Mental Health Data Sharing*
44. Clearview Research (2022) *Diverse Voices on Data*
45. The Liminal Space (2022) *Data Dialogues 2*

What next? Building confidence in a connected health data system

Public confidence is not produced by a single programme, data platform or engagement exercise. It is a system outcome. It depends on whether people can see clear benefits, understand who is responsible, trust the organisations involved, and believe their interests remain protected.

The future of health data will therefore be shaped not only by what the system can do, but by whether it can earn and sustain public confidence. To achieve this, we need:

1. A shared vision, architecture and public narrative

A more connected health data system needs more than a clearer public story. It needs a shared vision, coherent technical architecture and joined-up understanding across national organisations of how major programmes fit together. Future reform should be designed and explained in a way that reflects how people experience the system, rather than how institutions are organised. Communications can help people understand how initiatives such as the Single Patient Record, the Health Data Research Service and the NHS Federated Data Platform fit together, what each is intended to do and where their boundaries lie. But communications cannot substitute for clarity about the underlying model.

This means the public narrative must be built on genuine system coherence. If national bodies cannot clearly articulate the purpose of each programme, the relationships between them, the technical and governance architecture that connects them and the choices that remain open, those gaps will be visible to patients, professionals and the media. Better communications may make a coherent system more understandable; they cannot make an incoherent system trustworthy.

The narrative should not rely on benefits alone. People need straightforward answers about risks, trade-offs, commercial involvement, accountability, choices and what happens when things go wrong. Trust is not built by avoiding difficult questions; it is built by answering them clearly and showing how those answers are reflected in design, governance and implementation.

Communications also need to match how people now seek information. Information should be searchable, shareable and intelligible to the tools people use to make sense of complex issues, including AI search and large language models. Information should be easy enough to find, clear enough to quote, detailed enough to trust and structured enough to travel beyond an organisation's own website. The task for health data stewards is therefore not simply to communicate more, or to tell the story better, but to build the shared vision, develop joined-up plumbing and ensure governance clarity to make that story credible.

Recommendation:

The Department of Health and Social Care, NHS England and other national partners should develop a shared public account of the connected health data system, underpinned by a clear technical and governance architecture that explains how major initiatives in England relate to one another. This should be supported by a national transparency hub that explains the purpose, boundaries, governance, risks and public benefits of each programme in one place. Content should be accessible, open for reuse and optimised for large language models and AI.

2. Visible choice and accountable governance

Good governance should be visible, not something people are simply asked to trust. As national infrastructure develops, public confidence will depend not only on what organisations are legally allowed to do, but on whether people can see who decides, who scrutinises, what limits apply and how decisions can be challenged over time. Giving people a meaningful choice is part of taking accountability. Choices about data use need to be easy to find, understand and act on, including routes to opt out and opt back in. Where people choose to opt out, this should be treated as a signal of concern or caution, not simply as rejection of health data use. Those signals should help test whether the governance framework is sufficiently clear, responsive and trustworthy.

Recommendation:

The Health Bill offers a current legislative opportunity to make the governance framework for health data explicit, rather than leaving this to future guidance or implementation alone. Reform of the Health Service (Control of Patient Information) Regulations is also understood to be planned. These changes should clearly define the purposes for which health data can be used and reused, including by the Health Data Research Service, regional Secure Data Environments and wider Government infrastructure, both now and as future capabilities develop. They should set out who is accountable for decisions, where decisions will be subject to public involvement, the limits on data use and how individual choice, including the National data opt-out, will operate consistently across an increasingly interconnected health data system. The most important safeguards and red lines — including prohibitions on non-consented use for marketing or insurance purposes, and robust scrutiny of any wider cross-sector data sharing — should be transparent and embedded in law where appropriate.

3. People at the heart of decision-making

Public involvement should be part of decision-making throughout the life of health data initiatives. It should not be treated as a one-off exercise to secure support for a concept, or as a late-stage process focused only on communications.

People should have meaningful opportunities to shape acceptable uses of data, definitions of public benefit, governance arrangements and responses to controversial decisions.

Organisations should also show what changed as a result of patient and public involvement. Participation without visible outcomes risks reinforcing cynicism rather than building confidence.

Recommendation:

Patient and public involvement and engagement should be embedded across the full spectrum of health data use. Organisations should routinely evaluate and publicly report the impact of involvement activities, demonstrating how public perspectives have influenced decisions and what has changed as a result. Greater transparency about both the engagement and its impact is essential to building accountability, learning and public confidence.

After UPD completes its current project mapping patient and public involvement and engagement, we plan to hold a roundtable to co-develop recommendations for the health data sector and support greater public involvement in how health data is used.

4. Transparency that ensures no surprises

Health data reform is moving faster than public understanding. This creates a risk for implementation, not just communications. Programmes should build transparency in from the start, in line with legal duties and the 8th Caldicott Principle, so people know how their information is used in ways that are timely, meaningful, proportionate and not surprising.

This does not mean every programme needs to create its own engagement or communications work from scratch. As the system becomes more connected, transparency should be treated as a shared capability: something that can be reused, scaled and applied consistently across programmes. Before major programmes launch or expand, they should assess what the public understands, test public-facing information, and make sure trusted messengers, such as clinicians and local NHS organisations, can explain changes clearly.

People should have clear information about the purpose, benefits, governance, risks, responsibilities and choices before implementation. This should be proportionate to the programme's level of risk, novelty and public concern, while avoiding unnecessary duplication.

Good PPIE and transparency work takes time and resource, and should be properly valued, but programmes should also make use of existing evidence, reusable materials, shared public insight and common standards where appropriate.

Recommendation:

Every significant health data programme should demonstrate, before implementation, how it has met its transparency obligations, supported the 8th Caldicott Principle and enabled informed public understanding within the context of the wider system. National bodies should develop scalable, system-wide approaches to transparency and PPIE so programmes do not each reinvent the wheel. This should include shared evidence, reusable public-facing materials, common transparency standards and mechanisms for learning from previous engagement, while allowing activity to be proportionate to the programme's scale, risk and public salience.

5. To treat public confidence as a system outcome

Public confidence should be treated as a shared system outcome, requiring leadership across government, the NHS, regulators, researchers, charities and commercial partners. Trust lost in one part of the system can quickly affect confidence elsewhere.

The evidence base also needs strengthening. Gaps remain in longitudinal data on public attitudes, the perspectives of young people, the impact of intersecting inequalities on confidence, and public expectations of AI and emerging technologies. A stronger shared evidence base would help policymakers identify concerns earlier, evaluate interventions and respond before confidence is damaged.

Recommendation:

Public confidence should be adopted as a shared system outcome, supported by coordinated monitoring and investment in a stronger national evidence base. In support of this, UPD will routinely publish data from its public sentiment tracker and bring system-wide evidence together in a new Health Data Compass from Autumn 2026.

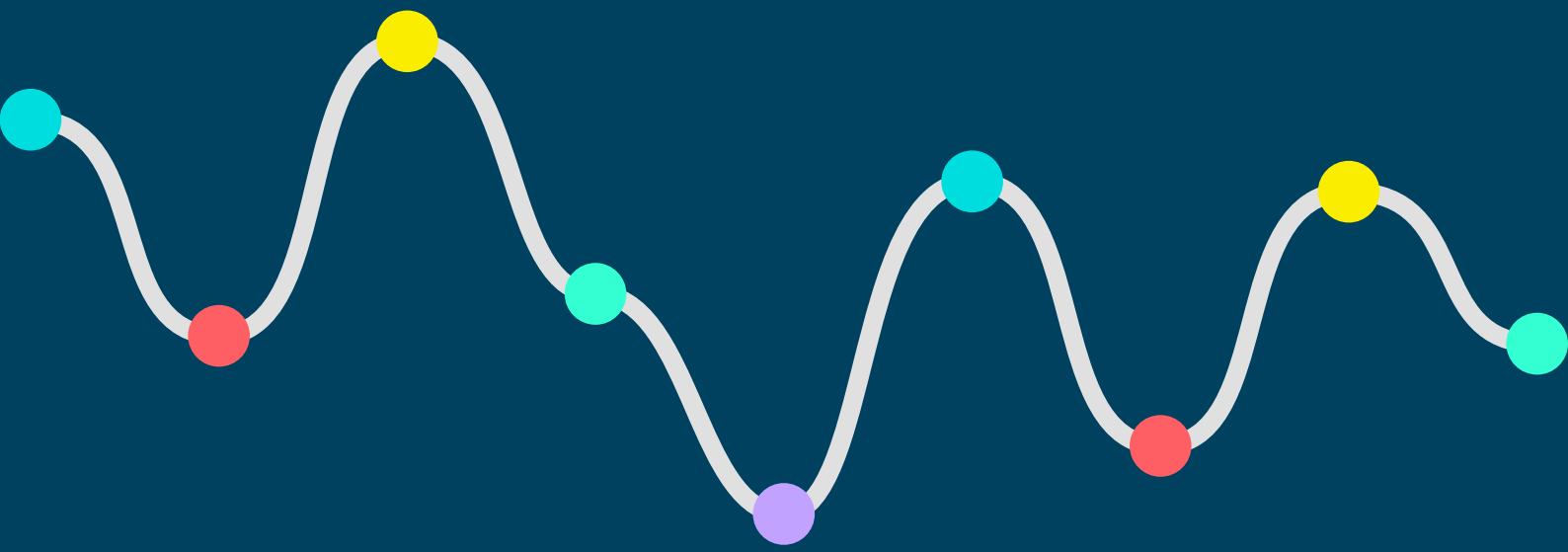
Conclusion: Taking shared responsibility for legitimacy

No single programme, organisation or engagement exercise can secure legitimacy on its own.

As health data becomes more connected, legitimacy must become a shared responsibility. Government, the NHS, regulators, researchers, charities, commercial partners, and the media, all shape whether people see the system as trustworthy.

The opportunity is significant. The public already recognises the potential value of better use of health data, particularly when it improves care, gives people greater access to their own information and strengthens the NHS.

The task now is to build a system that matches the public expectations: one where data are used responsibly, decisions are visible, benefits are clear and people have confidence not only in what the system can do, but also in how it is governed.



Appendix: Supporting evidence

This appendix provides an overview of key evidence informing the State of the Nation report, including indicative assessments of the evidence strength, illustrative findings, and key limitations, gaps and caveats to consider. The list of references is indicative, not exhaustive.

The evidence base is disproportionately derived from participants in England. Consequently, findings should be interpreted as reflecting the available evidence rather than representing all UK nations equally.

Public awareness and understanding of health data use

Strength of the evidence

- Consistent findings from across large-scale surveys, public dialogues and qualitative studies show that awareness of health data use beyond direct care remains low.
- Multiple studies have found widespread confusion about data opt-out mechanisms, data governance arrangements, how health data are used, and the formats in which data are shared and accessed.

What evidence tells us

Key evidence	Illustrative findings	Key supporting references
Awareness of health data use beyond direct care remains low.	61% of the UK public reported knowing "very little" or "nothing at all" about NHS data practices (Health Foundation, 2023). Under 30% of the public said they "definitely knew" that the NHS uses patient data beyond improving individual care (improving population health – 29%; planning and improving services – 27%; research and innovation – 26%) (NHS England, 2024). 57% do not recall ever receiving information about data held in GP records and 61% already believe a Single Patient Record exists (Qa Research and Understanding Patient Data, 2025). Only 17% correctly understood pseudonymisation and only 18% correctly understood a Type 1 opt-out (NHS Digital, 2022).	Health Foundation (2023) NHS Digital (2022) NHS England (2024) NHS England, Department of Health and Social Care, and Thinks Insight & Strategy (2025a) Qa Research and Understanding Patient Data (2024, 2025)

Evidence gaps and limitations

- The relationship between awareness, confidence, support and behaviour remains poorly understood.
- There is limited evidence about awareness and understanding about newer technologies and data systems.

Health data media narratives and their impact

Strength of the evidence

- There is strong evidence from media analyses that media coverage of health data use can influence public awareness, attitudes and levels of trust.

What evidence tells us

Key evidence	Illustrative findings	Key supporting references
Negative media coverage has wider reach than positive media coverage	Risk-focused narratives reach around 110 times the audience of benefit-focused stories Risk led reporting reaches c. 470m a month, vs. benefit-led reporting, which reaches c. 4.3m	Understanding Patient Data and Portland (2026)
Negative media can affect behaviour and opt outs.	During the GP Data for Planning and Research controversy in 2021, more than 1.3 million people chose to opt-out within a single month, taking the opt-out rate from 2.77% to 4.97%. 41% of respondents said that seeing the news stories about Palantir made them more likely to opt-out (or stay opted out), compared with 29% who said it did not (UPD 2026).	Tazare et al. (2024) Understanding Patient Data (2026)

Evidence gaps and limitations

- The evidence base is weaker about the long-term impact of media coverage and how public attitudes change over time in relation to media output.
- Mixed findings about how media influences awareness, support and behaviours (opt-out), which seems highly context dependant.

Public support for patient data use and key conditions

Strength of the evidence

- Consistent findings from more than a decade of UK research indicate strong but conditional public support for the use of health data. This conclusion is supported by surveys, systematic reviews and deliberative research, which also provides insight into the reasons underpinning public attitudes.
- The evidence base consistently identifies a number of recurring factors that shape public support for health data use.

What evidence tells us

Key evidence	Illustrative findings	Key supporting references
Strong support for data use – but conditional	92% supported the use of health data for medical research and 92% for healthcare planning (NatCen/ONS, 2025). 89% were happy for the NHS to use patient data to improve the care of others (NHS England, 2024). 90% were willing to share health data with the NHS for any purpose (Boston Consulting Group Centre for Growth, 2023).	Aitken et al. (2016) Boston Consulting Group Centre for Growth (2023) Health Foundation (2023) Kalkman et al. (2022) NatCen and ONS (2025) NHS England (2024) Understanding Patient Data (2026)
Conditions for public confidence	69% people said they trusted their GP practice with their data, vs. 34% national government (Health Foundation, 2023). 84% considered sharing health information with GPs and hospitals acceptable, compared with 23% for pharmaceutical companies and 20% for local councils (Yen et al., 2025).	Connected by Data (2023) Data Into Action (2025) Department for Science, Innovation and Technology (2024) Health Foundation (2023) Hopkins Van Mil and Understanding Patient Data (2021) Imperial College Health Partners and Ipsos (2021) Understanding Patient Data (2026) Ipsos (2025) Ipsos Scotland, 2025 Kuo et al. (2026) NHS England, Department of Health and Social Care, and Thinks Insight & Strategy (2025a, 2025c) OneLondon (2022) POST (2026) Shah et al. (2021) Sheehan et al. (2021) Stand and North East and North Cumbria ICB (2024, 2025) Understanding Patient Data, Involve and The Carnegie UK Trust (2018) Wessex Secure Data Environment (2024, 2025) Yen et al. (2025)

Key evidence	Illustrative findings	Key supporting references
Importance of meaningful public involvement in health data use	74% said the public should be involved in decisions about data partnerships. (Understanding Patient Data and Ada Lovelace Institute, 2020).	Hopkins Van Mil and Understanding Patient Data, 2021 NHS England, Department of Health and Social Care, and Thinks Insight & Strategy (2025a) OneLondon (2022) Understanding Patient Data and Ada Lovelace Institute (2020)

Evidence gaps and limitations

- Reported levels of public support vary across studies, partly because survey questions and research methods differ. As a result, evidence on how attitudes are changing over time remains limited and is difficult to infer from the existing body of research.
- The evidence base is strongest in relation to established uses of health data. Research on newer technologies and data infrastructures, such as artificial intelligence, large-scale data linkage and Secure Data Environments, is growing but remains less developed and mature.
- Much of the evidence on the factors influencing support for, or opposition to, health data use comes from deliberative research. While this approach provides valuable insights into how and why people form their views, participants are typically not representative of the wider population, and discussions are often focused on specific technologies, governance arrangements or commercial partnerships.

Behaviours and opt-out

Strength of the evidence

- Consistent findings from large-scale national studies and local engagement activities show that people want meaningful agency, transparency and accountability in decisions about how health data are used.
- Most of the evidence supporting these findings comes from qualitative and deliberative research, which enables participants to explore complex issues relating to health data use in depth. The desire for meaningful agency is a recurring theme across the evidence base, including studies focused on specific use cases, technologies and data-sharing arrangements.
- Recent large-scale deliberative programmes commissioned by NHS England have reinforced findings from earlier research, suggesting that the public's expectation for agency, transparency and accountability is a stable and enduring feature of attitudes towards health data use.

What evidence tells us

Key evidence	Illustrative findings	Key supporting references
People want meaningful agency and choice	89% supported having a single NHS mechanism allowing people to make choices about how their data are used (Jones et al., 2022).	Jones et al. (2022)
Existing opt-out arrangements confusing and difficult to navigate	N/A	NHS England, Department of Health and Social Care, and Thinks Insight & Strategy (2025c) OneLondon (2022) Qa Research and Understanding Patient Data (2025)
The desire for control is greater and where perceived risk is higher and perceived public benefit is lower.	N/A	NHS England, Department of Health and Social Care, and Thinks Insight & Strategy (2025c) University of Manchester and Patients' Association, 2023

Evidence gaps and limitations

- While people consistently express a desire for meaningful agency and choice in relation to health data use, preferences for consent and control are not uniform. Different individuals and communities have varying expectations about acceptable levels of risk, control and public benefit.
- The evidence highlights an ongoing tension between simplicity and granularity in governance approaches. Some studies suggest that people want more tailored and flexible choices about how their data are used, while others indicate support for simpler, easier-to-use mechanisms. As a result, the evidence is stronger on the principles people want to see reflected in governance and involvement arrangements than on which specific models are most effective in practice.
- Evidence on the impact of patient and public involvement and engagement (PPIE) remains relatively immature. Emerging research suggests that participation in engagement activities can increase confidence and understanding among those directly involved. However, there is less evidence on the longer-term effects of PPIE on trust, support or behaviour across the wider population.

Demographic differences

Strength of the evidence

- Consistent evidence from surveys, qualitative research and deliberative studies shows that confidence in health data use varies across different groups and communities. This evidence is drawn from both large-scale surveys and in-depth research with underserved and marginalised populations.
- Findings are broadly consistent across studies exploring differences linked to ethnicity, socioeconomic status, health conditions, levels of digital engagement and experiences of health and care services.
- There is strong evidence that previous experiences of healthcare, discrimination and inclusion shape levels of confidence in health data use, as well as perceptions of risk and willingness to share data. These experiences can influence whether individuals feel that health data systems are trustworthy, fair and likely to deliver benefits for people like them.

What evidence tells us

Key evidence	Illustrative findings	Key supporting references
People have different attitudes and confidence to health data.	57% of those aged 16-24 trusted NHS organisations with their data, rising to closer to 80% for those aged over 65 (Health Foundation 2023). 59% of men aware of health data being used for research vs 45% of women (UPD, 2026).	Creary et al. (2022) Health Foundation (2023) NatCen and ONS (2025) Understanding Patient Data (2026)
Attitudes to health data use is shaped by broader experience (including of health inequalities and discrimination)	N/A	Clearview Research (2022) Creary et al. (2022) Health Innovation Oxford & Thames Valley (2025a, 2025b) Kirkham et al. (2022) The Liminal Space (2022) Think Local Act Personal (2024) Understanding Patient Data, University of Worcester and Gate Herts (2025) Yorkshire & Humber Secure Data Environment (2024a, 2024b)

Evidence gaps and caveats

- Many of the insights on differences in attitudes and confidence come from targeted qualitative research with specific communities. These studies provide rich and valuable understanding of why attitudes vary, but they are not designed to be nationally representative and therefore have limitations in terms of generalisability.
- Some demographic findings are mixed across studies and appear to be influenced by context.
- Evidence on how differences in attitudes and confidence are changing over time remains limited. While there is clear evidence that views vary between groups, there is less robust evidence on whether these gaps are widening, narrowing or remaining stable.
- Research relating to some population groups remains underdeveloped. In particular, the evidence base contains notable gaps regarding the perspectives of younger people, especially those under 16 years of age, and individuals experiencing multiple and intersecting forms of disadvantage.

References

Aitken, M., de St. Jorre, J., Pagliari, C., Jepson, R., and Cunningham-Burley, S. (2016) 'Public responses to the sharing and linkage of health data for research purposes: a systematic review and thematic synthesis of qualitative studies', BMC Medical Ethics, 17(1). Available at: https://doi.org/10.1186/s12910-016-0153-x (Accessed: 16 July 2026).

BBC News (2026) UK Biobank health data listed for sale in China, government confirms. BBC News, 23 April 2026. Available at: https://www.bbc.co.uk/news/articles/cpvxgl3n138o (Accessed: 17 July 2026).

Boston Consulting Group Centre for Growth (2023) Towards a healthier, wealthier UK: Unlocking the value of healthcare data. Available at: https://web-assets.bcg.com/e7/10/3a81ba3340c98ff4be732f7f7667/towards-a-healthier-wealthier-uk-unlocking-the-value-of-healthcare-data.pdf (Accessed: 16 July 2026).

Clearview Research (2022) Diverse Voices on Data. A participatory research project: Exploring the views and experiences of Black and South Asian communities in the UK on patient data and its uses. Available at: https://www.understandingpatientdata.org.uk/sites/default/files/2022-04/Diverse%20voices%20on%20Data%20-%20Main%20report_0.pdf (Accessed: 16 July 2026).

Connected by Data (2023) Our Data Stories. Available at: https://connectedbydata.org/resources/our-data-stories (Accessed: 16 July 2026).

Creary, N., Amevenu, D., Shivji, J. and Henry C. H. (2022) What it means to be seen: Closing gaps in patient data for Black and South Asian Communities. Available at: https://www.understandingpatientdata.org.uk/sites/default/files/2023-02/Closing%20gaps%20in%20patient%20data%20for%20Black%20and%20South%20Asian%20communities.pdf (Accessed: 16 July 2026).

Data Into Action (2025) Public perspectives on non-traditional health data uses in Cheshire and Merseyside. Available at: https://dataintoaction.cheshireandmerseyside.nhs.uk/media/rjyd0smo/public-and-patient-perspectives-on-non-traditional-health-data-uses-report.pdf (Accessed: 16 July 2026).

Department for Science, Innovation and Technology (2024) Public attitudes to data and AI: Tracker survey (Wave 4) report. Available at: https://www.gov.uk/government/publications/public-attitudes-to-data-and-ai-tracker-survey-wave-4 (Accessed: 16 July 2026).

Eko (2026) Palantir polling, fieldwork conducted 6–7 July 2026. Unpublished data shared with Understanding Patient Data.

Health Foundation (2023) Exploring public attitudes towards the use of digital health technologies and data. Available at: https://www.health.org.uk/sites/default/files/pdf/2024-04/Exploring%20public%20attitudes%20towards%20the%20use%20of%20digital%20health%20technologies%20and%20data.pdf (Accessed: 16 July 2026).

Health Innovation Oxford & Thames Valley (2025a) Gypsy, Roma & Travellers: Attitudes to Healthcare Data for Planning & Research. Available at: https://thamesvalleyandsurreyhealthandcaredata.nhs.uk/920-2/ (Accessed: 16 July 2026).

Healthwatch England (2026). What does the public think about AI scribe use in healthcare? Available at: https://www.healthwatch.co.uk/blog/2026-07-16/what-does-public-think-about-ai-scribe-use-healthcare (Accessed: 22 July 2026).

Health Innovation Oxford & Thames Valley (2025b) Homelessness Attitudes to Healthcare Data for Planning & Research. Available at: https://www.healthinnovationoxford.org/wp-content/uploads/2026/02/Homelessness-Atthitudes-to-healthcare-data-for-planning-and-research-report.pdf (Accessed: 16 July 2026).

Hopkins Van Mil and Understanding Patient Data (2021) Putting Good into Practice: A public dialogue on making public benefit assessments when using health and care data. Available at: https://www.gov.uk/government/publications/putting-good-into-practice-a-public-dialogue-on-making-public-benefit-assessments-when-using-health-and-care-data (Accessed: 16 July 2026).

Imperial College Health Partners and Ipsos (2021) Discover NOW Citizens Advisory Group: Deliberation 1 Report. Available at: https://imperialcollegehealthpartners.com/wp-content/uploads/2021/03/Discover-NOW-Citizens-Advisory-Group_Deliberation-1_Report_Feb2021.pdf (Accessed: 16 July 2026).

Ipsos (2025) Ipsos Veracity Index 2025. Available at: https://www.ipsos.com/en-uk/ipsos-veracity-index-2025 (Accessed: 15 July 2026).

Ipsos, British Science Association and UK Research and Innovation (2025) Public Attitudes to Science 2025. Available at: https://pas.ipsos.com (Accessed: 20 July 2026).

Ipsos Scotland (2025). Public opinions on accessing public sector data for research in the public good: Findings from deliberative workshops. Available at: https://www.researchdata.scot/media/mcdpjc1v/public-opinions-on-accessing-public-sector-data-for-research-in-the-public-good-september-2025.pdf (Accessed: 15 July 2026).

Jones, L.A., Nelder, J. R., Fryer, J. M., Alsop, P. H., Geary, M. R., Prince, M., and Cardinal, R. N. (2022) 'Public opinion on sharing data from health services for clinical and research purposes without explicit consent: an anonymous online survey in the UK', BMJ Open, 12(4). Available at: https://bmjopen.bmj.com/content/12/4/e057579

Kalkman, S. van Delden, J., Banerjee, A., Tyl, B., Mostert, M., and van Thiel, G. (2022) 'Patients' and public views and attitudes towards the sharing of health data for research: a narrative review of the empirical evidence', Journal of Medical Ethics, 48(1). Available at: https://doi.org/10.1136/medethics-2019-105651

Kirkham, E. J., Lawrie, S. M., Crompton, C. J., Iveson, M. H., Jenkins, N. D., Goerdten, J., Beange, I., Chan, S. W. Y., McIntosh, A., and Fletcher-Watson, S. (2022) 'Experience of clinical services shapes attitudes to mental health data sharing: findings from a UK-wide survey', BMC Public Health, 22(1). Available at: https://doi.org/10.1186/s12889-022-12694-z

Kuo, R., O'Hanlon, C., Smith, J., Hill, R., Papiez, B. W., Collins, G. S., Furniss, D., and Tutton, E. (2026) 'Public perceptions of health data sharing for artificial intelligence research: a qualitative focus group study in the UK', BMJ Digital Health & AI, 2(1). Available at: https://bmjdigitalhealth.bmj.com/content/2/1/e000239 (Accessed: 28 April 2026).

Lammons, W., Buffardi, A.L. and Marks, D. (2025) 'Measuring impacts of patient and public involvement and engagement (PPIE): a narrative review synthesis of review evidence', Research Involvement and Engagement, 11(1). Available at: https://doi.org/10.1186/s40900-025-00748-6

NatCen and ONS (2025) Public Attitudes Towards Data Use in Statistics. Available at: https://natcen.ac.uk/ONShealthdata (Accessed: 28 April 2026).

National Data Guardian (2016) Review of Data Security, Consent and Opt-Outs. Available at: https://assets.publishing.service.gov.uk/media/5a7502feed915d3c7d529b39/data-security-review.PDF (Accessed: 15 July 2026).

National Data Guardian (2020) The Caldicott Principles. Department of Health and Social Care. Available at: https://www.gov.uk/government/publications/the-caldicott-principles (Accessed: 15 July 2026).

National Data Guardian (2026) National Data Guardian statement on NHS Federated Data Platform data access, in response to the Not With My NHS Data campaign. Available at: National Data Guardian statement on NHS Federated Data Platform data access, in response to the Not With My NHS Data campaign – GOV.UK (Accessed: 15 July 2026).

NHS Digital (2022) Public survey summary report: General Practice Data for Planning and Research (GPDPR). Available at: https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/gpdpr-programme-reports-and-publications/public-survey-summary-report (Accessed 16 July 2026).

NHS England (2024) Public attitudes to data in the NHS and social care. Available at: https://digital.nhs.uk/data-and-information/keeping-data-safe-and-benefitting-the-public/public-attitudes-to-data-in-the-nhs-and-social-care (Accessed: 27 April 2026).

NHS England, Department of Health and Social Care and Thinks Insight & Strategy (2025a) National public engagement on the use of health and care data: Cohort 1 – principles of data use and access. Available at: https://transform.england.nhs.uk/key-tools-and-info/data-saves-lives/national-public-engagement-on-the-use-of-health-data/national-engagement-on-data-cohort-2-report (Accessed: 28 April 2026).

NHS England, Department of Health and Social Care and Thinks Insight & Strategy (2025b) National engagement on data: Cohort 2 – Linking primary and secondary care data. Available at: https://transform.england.nhs.uk/key-tools-and-info/data-saves-lives/national-public-engagement-on-the-use-of-health-data/national-engagement-on-data-cohort-2-report (Accessed: 28 April 2026).

NHS England, Department of Health and Social Care and Thinks Insight & Strategy (2025c) National engagement on data: Cohort 3 – The opt out landscape and patient choice. Available at: https://digital.nhs.uk/data-and-information/keeping-data-safe-and-benefitting-the-public/national-public-engagement-in-the-use-of-health-and-care-data/cohort-3---the-opt-out-landscape-and-patient-choice (Accessed: 15 July 2026).

NHS England, Department of Health and Social Care and Thinks Insight & Strategy (2026) National engagement on data: Cohort 4 – Linking health and non-health data. Available at: https://digital.nhs.uk/data-and-information/keeping-data-safe-and-benefitting-the-public/national-public-engagement-in-the-use-of-health-and-care-data/cohort-4---linking-health-and-non-health-data (Accessed: 28 April 2026).

NHS England Digital (2026) National data opt-out open data dashboard. Available at: https://digital.nhs.uk/dashboards/national-data-opt-out-open-data (Accessed: 15 July 2026).

OneLondon (2022) A deliberation on London's health and care data. Available at: https://www.onelondon.online/wp-content/uploads/2022/10/A-deliberation-on-Londons-health-and-care-data_FINAL.pdf (Accessed: 15 July 2026).

Understanding Patient Data and Portland Communications (2026) Health Data in the Headlines: a changing media landscape (July 2026). Available at: https://www.understandingpatientdata.org.uk/health-data-in-the-headlines (Accessed: 21 July 2026).

Parliamentary Office of Science and Technology (POST) (2026) Accessing National Health Data for Research, POSTnote 774. Available at: https://researchbriefings.files.parliament.uk/documents/POST-PN-0774/POST-PN-0774.pdf (Accessed: 17 July 2026)

Qa Research and Understanding Patient Data (2024) Using Patient Data for Planning and Population Health: Views from the UK general public. Available at: https://www.understandingpatientdata.org.uk/sites/default/files/2025-05/UPD_GP_Data_Report_Final.pdf (Accessed: 15 July 2026).

Qa Research and Understanding Patient Data (2025) Public Perspectives on GP Record Data: Exploring views and information needs about patient data held in general practice records in England. Available at: https://www.understandingpatientdata.org.uk/sites/default/files/2025-05/UPD_GP_Data_Report_Final.pdf (Accessed: 15 July 2026).

Shah, N., Viberg Johansson, J., Haraldsdóttir, E., Bentzen, H. B., Coy, S., Mascalzoni, D., Jónsdóttir, G. A., and Kaye, J. (2021) 'Governing health data across changing contexts: A focus group study of citizen's views in England, Iceland, and Sweden', International Journal of Medical Informatics, 156. Available at: https://doi.org/10.1016/j.ijmedinf.2021.104623

Sheehan, M. Thompson, R., Kelly, M., Fitzgerald, R., Pitman, A., Curtis, H. J., Goldacre, B., and Murtagh, M. J. (2021) 'Trust, trustworthiness and sharing patient data for research', Journal of Medical Ethics, 47(12), pp. e26–e26. Available at: https://doi.org/10.1136/medethics-2019-106048

Stand and North East and North Cumbria ICB (2024) Secure Data Environment for the North East and North Cumbria: Demographic Street Survey. Available at: https://northeastnorthcumbria.nhs.uk/media/m3nlmmt0/20240229_sde-demographic-street-survey-final_v10.pdf (Accessed: 15 July 2026).

Stand and North East and North Cumbria ICB (2025) North East and North Cumbria Secure Data Environment: Targeted Engagement – findings. Available at: https://northeastnorthcumbria.nhs.uk/media/moiatisw/nenc-sde-targeted-engagement-findings-april-2025-focus-grp-final-publish.pdf (Accessed: 15 July 2026).

Stockdale, J., Cassell, J. and Ford, E. (2018) '"Giving something back": A systematic review and ethical enquiry into public views on the use of patient data for research in the United Kingdom and the Republic of Ireland'. Wellcome Open Research. Available at: https://doi.org/10.12688/wellcomeopenres.13531.2 (Accessed: 15 July 2026).

Sylvester, R., Hayward, E. and Lambert, G. (2024) Public back "patient passports" to share medical records with any doctor. Available at: https://www.thetimes.com/uk/healthcare/article/nhs-data-shared-freely-times-health-commission-bqhrfwh83 (Accessed: 15 July 2026).

Tazare, J., Henderson, A.D., Morley, J., Blake, H.A., McDonald, H.I., Williamson, E.J. and Strongman, H. (2024) 'NHS National data opt-outs: trends and potential consequences for health data research', BJGP Open, 8(3). https://doi:10.3399/BJGPO.2024.0020

The Liminal Space (2022) Data Dialogues 2. Available at: https://www.digihealthcare.scot/app/uploads/2022/03/FINAL-Data-Dialogues-Report-compressed.pdf (Accessed: 15 July 2026).

Think Local Act Personal (2024) Data for People: Principles and priorities for the collection, storage, sharing and use of data around care and support. Available at: https://thinklocalactpersonal.org.uk/resources/data-for-people/ (Accessed: 15 July 2026).

Understanding Patient Data (2026) UK Patient Data Sentiment Tracker: Wave 3 Findings (May 2026). Available at: https://www.understandingpatientdata.org.uk/uk-patient-data-sentiment-tracker-wave-3 (Accessed: 21 July 2026)

Understanding Patient Data and Ada Lovelace Institute (2020) Foundations of Fairness: views on uses of NHS patients' data and NHS operational data. Available at: https://www.understandingpatientdata.org.uk/sites/default/files/2020-03/Foundations%20of%20Fairness%20-%20Full%20Research%20Report.pdf (Accessed: 15 July 2026).

Understanding Patient Data, Involve and The Carnegie UK Trust (2018) Data for Public Benefit: Balancing the risks and benefits of data sharing. Available at: https://www.understandingpatientdata.org.uk/sites/default/files/2018-04/Data%20for%20public%20good_0.pdf (Accessed: 15 July 2026).

Understanding Patient Data, University of Worcester and Gate Herts (2025) Equitable Data Collection for Gypsy, Roma and Traveller Communities in Health Services: Community-centred and informed ethnicity data categorisation. Available at: https://www.understandingpatientdata.org.uk/sites/default/files/2025-01/FINAL%20REPORT_4.pdf (Accessed: 17 July 2026).

University of Manchester and Patients' Association (2023) General Practice Data Trust (GPDT) Projects. Available at: https://www.socialsciences.manchester.ac.uk/csep/research/projects/gpdt-pilot-study (Accessed: 28 April 2026).

Wessex Secure Data Environment (2024) Listening to Seldom Heard Groups across Wessex. Available at: https://wessexsde.nhs.uk/wp-content/uploads/2026/01/Wessex-SDE-Listening-to-Seldom-Heard-Groups-across-Wessex-June-2024.pdf (Accessed: 15 July 2026).

Wessex Secure Data Environment (2025) Wessex Public Panel on NHS Data: Final Report. Available at: https://wessexsde.nhs.uk/wp-content/uploads/2025/12/Wessex-Public-Panel-on-NHS-Data-Final-Report.pdf (Accessed: 15 July 2026).

Yen, D., Dorussen, H., Pickering, S., Hansen, M., Scotto, T., and Reifler, J. (2025) 'Public attitudes towards disclosing personal and anonymous health-related data and information', British Journal of Healthcare Management, 31(1). Available at: https://www.magonlinelibrary.com/doi/10.12968/bjhc.2024.0056

Yorkshire & Humber Secure Data Environment (2024a) Secure Data Environment Community Workshop Report by Connecting Roma. Available at: https://yorkshirehumbersde.nhs.uk/wp-content/uploads/2024/12/SDE-Workshop-Report-Connecting-Roma.pdf (Accessed: 16 July 2026).

Yorkshire & Humber Secure Data Environment (2024b). Secure Data Environment Community Workshop Report by OutLoud. Available at: https://yorkshirehumbersde.nhs.uk/wp-content/uploads/2024/12/SDE-Report-OutLOUD.pdf (Accessed: 16 July 2026).

Understanding Patient Data

Supporting reports

Alongside *Understanding Patient Data in 2026: navigating public confidence in a changing health data system*, UPD has published two companion reports that provide deeper insight into key areas of the evidence base.

UK Patient Data Sentiment Tracker: Wave 3 Findings presents findings from UPD's nationally representative polling programme, tracking public awareness, confidence, trust and support for health data use over time. The report explores attitudes towards topics including data security, opt-outs, NHS partnerships, emerging technologies and major health data initiatives.

Health data in the headlines: a changing media landscape produced with Portland, examines how health data is discussed across national media, trade media, social media and AI platforms. The report explores the narratives shaping public debate, the issues receiving greatest attention, and the role that media coverage plays in influencing public confidence and perceptions of risk.

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About UPD

Understanding Patient Data (UPD) is an independent initiative with a mission to make the use of patient data more visible, understandable and trustworthy, so it can be used well, responsibly and for public benefit. UPD is a hosted organisation of the NHS Alliance in London. UPD's core work is funded by Wellcome, the Medical Research Council, the National Institute for Health and Care Research, NHS England, the Department of Health and Social Care, and the Office for Life Sciences.

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